



National Institute of Allergy and Infectious Diseases
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Chronic Fatigue Syndrome

What is Chronic Fatigue Syndrome?

We all get tired. Many of us at times have felt depressed. But the mystery known as chronic fatigue syndrome (CFS) is not like the normal ups and downs we experience in everyday life. The early sign of this illness is a strong and noticeable fatigue that comes on suddenly and often comes and goes or never stops. You feel too tired to do normal activities or are easily exhausted with no apparent reason. Unlike the mind fog of a serious hangover, to which researchers have compared CFS, the profound weakness of CFS does not go away with a few good nights of sleep. Instead, it slyly steals your energy and vigor over months and sometimes years.

How CFS Begins and Its Symptoms

For many people, CFS begins after a bout with a cold, bronchitis, hepatitis, or an intestinal bug. For some, it follows a bout of infectious mononucleosis, or mono, which temporarily saps the energy of many teenagers and young adults. Often, people say that their illnesses started during a period of high stress. In others, CFS develops more gradually, with no clear illness or other event starting it.

Unlike flu symptoms, which usually go away in a few days or weeks, CFS symptoms either hang on or come and go frequently for more than six months. CFS symptoms include:

- ✦ Headache
- ✦ Tender lymph nodes
- ✦ Fatigue and weakness
- ✦ Muscle and joint aches
- ✦ Inability to concentrate

Who Gets CFS?

CFS was once stereotyped as a new "yuppie flu" because those who sought help for and caused scientific interest in CFS in the early 1980s were mainly well-educated, well-off women in their thirties and forties. Similar illnesses, known by different names, however, date back at least to the late 1800s. The modern stereotype arose. Since then, doctors have seen the syndrome in people of all ages, races, and social and economic classes from several countries around the world.

Still, CFS is diagnosed two to four times more often in women than in men, possibly

because of biological, psychological, and social influences. For example,

- ✦ CFS may have a gender difference similar to diseases such as systemic lupus erythematosus and multiple sclerosis, which affect more women than men.
- ✦ Women may be more likely than men to talk with their doctors about CFS-like symptoms.
- ✦ Some members of the medical community and the public do not know about or are skeptical of the syndrome.
- ✦ An increasingly diverse patient group will likely emerge as more doctors see CFS as a real disorder.

How Many People Have It?

Because there is no specific laboratory test or clinical sign for CFS, no one knows how many people this illness affects. CDC estimates, however, that as many as 500,000 people in the United States have a CFS-like condition.

What Causes CFS?

While no one knows what causes CFS, for more than a century, doctors have reported seeing illnesses similar to it. In the 1860s, Dr. George Beard named the syndrome neurasthenia because he thought it was a nervous disorder with weakness and fatigue. Since then, health experts have suggested other explanations for this baffling illness.

- ✦ Iron-poor blood (anemia)
- ✦ Low blood sugar (hypoglycemia)
- ✦ Environmental allergy
- ✦ A body wide yeast infection (candidiasis)

In the mid-1980s, the illness became labeled "chronic EBV" when laboratory clues led scientists to wonder whether the Epstein-Barr virus (EBV) might be causing this group of symptoms. New evidence soon cast doubt on the theory that EBV could be the only thing causing CFS. High levels of EBV antibodies (disease-fighting proteins) have now been found in some healthy people as well as in some people with CFS. Likewise, some people who don't have EBV antibodies, and who thus have never been infected with the virus, can show CFS symptoms.

How is CFS Diagnosed?

Doctors find it difficult to diagnose CFS because it has the same symptoms as many other diseases. When talking with and examining you, your doctor must first rule out diseases that look similar, such as multiple sclerosis and systemic lupus erythematosus in which symptoms can take years to develop. In follow-up visits, you and your doctor need to be alert to any new cues or symptoms that might show that the problem is something other than CFS.

When other diseases are ruled out and if your illness meets other criteria as well, your doctor can diagnose you with CFS (see *The CFS Case Definition*).

The CFS Case Definition

The EBV work sparked new interest in the syndrome among a small group of medical researchers. They realized they needed a standard way to describe CFS so that they could more easily compare research results.

In the late 1980s, CDC brought together a group of CFS experts to tackle this problem. Based on the best information available at the time, this group published in the March 1988 issue of the scientific journal, *Annals of Internal Medicine*, strict symptom and physical criteria -- the first case definition -- by which scientists could evaluate CFS study patients.

Not knowing the cause or a specific sign for the disease, the group agreed to call the illness "chronic fatigue syndrome" after its primary symptom. "Syndrome" means a group of symptoms that occur together but can result from different causes. (Today, CFS also is known as myalgic encephalomyelitis, postviral fatigue syndrome, and chronic fatigue and immune dysfunction syndrome.)

After using this definition for several years, CFS researchers realized some criteria were unclear or redundant. An international group of CFS experts reviewed the criteria for CDC, which led to the first changes in the case definition. This new definition was published in the same journal in December 1994.

Besides revising the CFS case criteria -- which reduced the required minimum number of symptoms to four out of a list of eight possible symptoms -- the newer report also proposed a conceptual outline for studying the syndrome. This outline recognizes CFS as part of a range of illnesses that have fatigue as a major symptom. Although primarily intended for researchers, these guidelines should help doctors better diagnose CFS.

How Can I Cope With and Manage the Illness?

There is no effective treatment for CFS. Even though there is no specific treatment for CFS itself, you may find it quite helpful to treat your symptoms. Nonsteroidal anti-inflammatory drugs, such as ibuprofen, may help get rid of any body aches or fever, and nonsedating antihistamines may help relieve any prominent allergic symptoms, such as runny nose.

Learning how to manage your fatigue may help you improve the level at which you can function and your quality of life despite your symptoms. A rehabilitation medicine specialist can evaluate and teach you how to plan activities to take advantage of times when you usually feel better.

The lack of any proven effective treatment can be frustrating to both you and your doctors. If you have CFS, health experts recommend that you try to maintain good health by:

- ✦ Eating a balanced diet and getting adequate rest
- ✦ Exercising regularly but without causing more fatigue

- Pacing yourself -- physically, emotionally, and intellectually -- because too much stress can aggravate your symptoms. The course of CFS varies from patient to patient

For most people, CFS symptoms plateau early in the course of illness and thereafter wax and wane. Some people get better completely, but it is not clear how frequently this happens. Emotional support and counseling can help you and your loved ones cope with the uncertain outlook and the ups and downs of this illness.

New studies seem to show that cognitive behavioral therapy and graduated exercise programs can greatly help many. Others are helped by antidepressants.

Because well-designed clinical studies have found that patients with fibromyalgia (an illness similar to CFS) benefit from low-dose tricyclic antidepressants, doctors often prescribe these drugs for people with CFS with generally positive results. Some researchers believe that these drugs improve the quality of sleep. Patients also have benefited from other kinds of antidepressants, including the newer serotonin reuptake inhibitors. Therapeutic doses of antidepressants often increase fatigue in CFS, so doctors may have to increase the dosage very slowly, or prescribe more active antidepressants. In addition, some people with CFS benefit from the benzodiazepines, a class of drugs used to treat acute anxiety and sleep problems. Patients often try more than one drug before finding one that works and can be tolerated.

Conclusion

CFS seems to involve interactions between the immune and central nervous systems, interactions about which scientists know relatively little. Scientists' concerted efforts to penetrate the complex nervous system and immune system events in CFS have created a challenging new concept of the pathology of this and other illnesses.

For More Information About CFS

MEDLINEplus is the **National Library of Medicine** Web site designed to direct you to information resources that will help you research your health questions. It includes a searchable database of published medical literature called MEDLINE.

1-800-338-7657

<http://www.nlm.nih.gov/medlineplus/>

Centers for Disease Control and Prevention

National Center for Infectious Diseases
Division of Viral and Rickettsial Diseases
Atlanta, GA 30333
404-639-1388 or 1-888-232-3228
<http://www.cdc.gov/ncidod/diseases/cfs>

Disability Benefits

Clearinghouse on Disability Information

Office of Special Education and Rehab Services
U.S. Department of Education
Room 3132, Switzer Building
Washington, DC 20202
212-205-8241

U.S. Social Security Administration

Call your local social security office or
1-800-772-1213 (7:00 am - 7:00 pm ET weekdays)
<http://www.ssa.gov>

Social Security pays disability benefits under two programs: the Social Security Disability Insurance Program and the Supplemental Security Income (SSI) Program. Medical requirements for disability payments under both programs are the same. Eligibility for Social Security disability is based on prior work history and SSI payments are made on the basis of financial need.

National Organization of Social Security Claimants Representatives

(NOSSCR -- a lawyer referral source)
1-800-431-2804

Finding a Doctor

University-affiliated medical schools may help in locating physicians who can evaluate symptoms or who can provide an appropriate referral.

NOTE: The following groups are listed solely for your information because of their interest in chronic fatigue syndrome. This list does not constitute an endorsement of the organizations or any of their referrals, products, or services.

National CFS Patient Organizations

Chronic Fatigue and Immune Dysfunction Syndrome Association of America

P.O. Box 220398
Charlotte, NC 28222
1-800-442-3437
<http://www.cfids.org>

National Chronic Fatigue Syndrome and Fibromyalgia Association

P.O. Box 18426
Kansas City, MO 64133
816-313-2000

Health Professional Organizations

American Association for Chronic Fatigue Syndrome

325 Ninth Avenue
Box 359780

Seattle, WA 98104
206-781-3544

The objectives of AACFS are to promote, stimulate and coordinate the exchange of ideas related to CFS research, patient care and treatment, and to periodically review the current CFS clinical, research, and treatment literature as well as information on CFS released by the media, for the benefit of CFS patients and interested scientists and clinicians. Clinicians as well as research and health care workers professionally engaged in CFS activities may apply for regular membership.

New Jersey Chronic Fatigue Syndrome Center

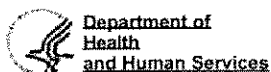
Dr. Benjamin Natelson
University of Medicine and Dentistry
MSB H-506
185 S. Orange Avenue, University Heights
Newark, NJ 07103-2714
973-972-5864

The goals of the New Jersey CFS Center are to provide a multidisciplinary approach to the evaluation, diagnosis and treatment of persons with CFS; to perform research geared towards finding the underlying causes of CFS and the effective treatment of the debilitating symptoms associated with the illness; and to educate patients, families, health care professionals and the general public concerning research, treatment practices and coping mechanisms.

NIAID is a component of the National Institutes of Health (NIH), which is an agency of the Department of Health and Human Services. NIAID supports basic and applied research to prevent, diagnose, and treat infectious and immune-mediated illnesses, including HIV/AIDS and other sexually transmitted diseases, illness from potential agents of bioterrorism, tuberculosis, malaria, autoimmune disorders, asthma and allergies.

News releases, fact sheets and other NIAID-related materials are available on the NIAID Web site at <http://www.niaid.nih.gov>.

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